



Reconciling cultural conflicts: Asian American parent responses to perinatal loss

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ABSTRACT

Perinatal loss is a frequently underacknowledged bereavement experience with profound consequences, especially for Asian American families navigating conflicting cultural expectations. This qualitative descriptive study aims to explore Asian American couples' experiences with and responses to perinatal loss. Semi-structured interviews from seven participants representing six Asian American families were transcribed, coded, and thematically analyzed by two investigators. Three domains, four overlapping themes, and nine subthemes emerged. In the domain of External Influences, Sociocultural Context dictated norms and acceptable behaviors and practices. Within the domain of Individualized Parental Responses, Perinatal Parenting and Coping with Loss drove parental actions. At times, these responses conflicted with Sociocultural Context, resulting in the domain, Areas of Conflict. Parents were then tasked with Reconciling Conflicts, where parents found solace through decision making, supportive communities, and continued relationships with their lost infants. We offer recommendations for supporting Asian American families who are navigating the complexities of perinatal loss.

Introduction

The loss of a fetus or neonate can lead to profound, persistent, and life-altering consequences for bereaved families. In the US, perinatal mortality occurs in 5.69 per 1,000 live births (Valenzuela et al., 2022). Perinatal loss is a collective term for *miscarriage* (defined as a loss of a baby prior to the 20th week of pregnancy), *stillbirth* (a loss of a baby after 20 weeks of pregnancy), and *neonatal death* (a loss of a baby within the first 28 days of life) (Berry, 2022). Also included are parents who chose termination for life-limiting fetal diagnoses; for these parents, rates vary widely amongst studies. The impacts of perinatal loss are substantial to individuals and important global health topics (Flenady et al., 2011, Frøen et al., 2011). The impacts can be physical (Li et al., 2003), psychological (Boyle et al., 1996, Armstrong, 2001, Li et al., 2005, Badenhorst & Hughes, 2007, Lacasse & Cacciato, 2014), emotional (Hunfeld et al., 1995, Armstrong, 2002, Burden et al., 2016, Furtado-Eraso et al., 2021), social (Gold et al., 2010, Fernández-Sola et al., 2020),

spiritual (Arnold & Gemma, 2008, Bakker & Paris, 2013, Allahdadian & Irajpour, 2015, Alvarenga et al., 2021, Wright, 2020, Kain, 2021), and financial (Heazell et al., 2016).

Perinatal loss can be perceived quite differently by parents, families, the surrounding community, and the overarching culture, and these differences can increase stress and complicate bereavement (Frøen et al., 2011, Punaglom et al., 2022). Parents who anticipated a joyous delivery of a new life are instead confronted with intense grief, which is often invisible to society (Capitulo, 2005). Persistent social stigma and blame (Doka, 1989) often lead parents to profound feelings of isolation and alienation (Kobler et al., 2007, Brierley-Jones et al., 2014, Markin & Zilcha-Mano 2018, Shannon & Wilkinson, 2020). Recognizing and responding to these complex aspects of perinatal loss (Betz & Thorngren, 2006, Mostrenko, 2020) can help providers guide therapeutic relationships with bereaved parents to foster their healing (Shannon & Wilkinson, 2020). Parents report better outcomes when they are

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offered opportunities to foster a relationship with their deceased baby by holding the infant, taking photos, and making or receiving mementos (Capitulo, 2005, Gold et al., 2007, Miller et al., 2014, LeDuff et al., 2017, Goldstein et al., 2020).

Asian Americans compose 7% of the U.S. population and represent a diverse group with great heterogeneity within America. Their ancestries originate from over 20 countries from South, Southeast, and East Asia. Of these, Chinese Americans account for the majority of Asian Americans, followed by Indian Americans, Filipino Americans, Vietnamese Americans, Korean Americans, and Japanese Americans (Jan 2024). The unique experiences and needs of Asians within the US have received little attention, and previous perinatal research has focused on the experiences of women residing in Asia (Hsu et al., 2002, Hsu et al., 2004, Chan et al., 2010, Tseng et al., 2018, Punaglom et al., 2022). An exception includes the work of Ng (2021), who interviewed Chinese American women, noting that Asian cultural factors, such as cultural superstition, shame and embarrassment, and feelings of blame for the infant loss, contributed to feelings of discounted and disenfranchised grief. For these women, efforts to adapt and integrate beliefs from the Western culture facilitated emotional recovery. Grief is an inherently human experience that is influenced by one's cultural context, within which parents find individualized ways to cope, mitigating pathological grief and promoting better health outcomes (Cacciatore, 2009, Boyden et al., 2014, Meyer et al., 2018, Fenstermacher & Hupcey, 2019, Madden-Stribling, 2021, Punaglom et al., 2022, Okumura et al. 2024).

In this study, we aim to understand the unique perinatal loss experiences of Asian Americans that are related to their cultural heritage within U.S. society. A secondary aim is to understand the perinatal death beliefs, rituals, practices, and methods of coping of these parents in order to illuminate the responses of bereaved Asian American couples to perinatal loss. Our findings are intended to inform health care workers who support these parents through their pregnancies and bereavement.

Materials and methods

Design

A qualitative descriptive study was conducted that included 6 Asian American families who had experienced a perinatal or infant loss. Semi-structured interviews, conducted virtually via Zoom, were used to elicit participants' experiences.

Participant inclusion and exclusion criteria

Parents were selected for the study based on the following inclusion criteria: (1) Age > 18 years; (2) at least one parent self-identified as Asian American; (3) couple had experienced a miscarriage, stillbirth or infant loss up to 6 months of age; (4) loss occurred > 6 months prior to the onset of the study. The only exclusion criterion was the inability to communicate in English. Parents who responded were asked if their partner was interested in participating.

Recruitment

Participants were recruited by network sampling over a 9-month period in 2022–2023. Recruitment fliers were posted on two social media sites: Perinatal Hospice and Palliative Care Continuing Your Pregnancy (n.d.) and Return to Zero H.O.P.E (n.d.), which has online support groups for women of color. The researchers (BJ, EDK) also notified Asian religious and cultural centers about the study and emailed study information to perinatal palliative care centers in areas of the country with a high percentage of Asian Americans. The organizers were encouraged to forward flyers to anyone meeting criteria whom they thought might be interested. Network sampling allowed word-of-mouth sharing of recruitment resources in hopes of reaching a broader sample of Asian American parents. An effort was made to find parents from different Asian countries of origin and to improve transferability of findings.

Ethical considerations

The University of Rochester Institutional Review Board approved the study as minimal risk. The parents were given an information sheet in advance that described the purpose and nature of the study, explained that participation in the study was voluntary, notified that there was potential emotional difficulty in discussing the loss, and informed that no compensation was offered for participation in the study. Verbal consent was obtained for each parent that participated.

Guided interviews

Semi-structured interviews were conducted virtually over Zoom with one researcher leading and the second observing. After collection of information on

Table 1. Interview guide.

1. Tell me about your loss(es) from the beginning (i.e. share your story).
2. Tell me about your religion or culture.
3. How does that religion or culture help (or not help) you with your loss?
4. How did your family and friends respond? What was helpful or unhelpful?
5. Is there guidance in your culture for what to do when faced with a perinatal loss? Would it be different if you had a miscarriage vs. stillbirth vs. liveborn infant?
6. When does your religion/culture believe a fetus or baby becomes a person? Does the fetus, for example, have a soul?
7. Where do you believe your baby is now?
8. Is burial or cremation typical? Are there any specific steps done before the death? What about between the death and the burial/cremation (i.e. washing, donning special clothing or blankets, holding a vigil/staying with the body)?
9. Is there a funeral or other ceremony that others attend?
10. Do you have any keepsakes or photos in your home?

demographics and the religious and cultural affiliation of participant(s) and partner, the interviews followed the interview guide in Table 1. The interview guide was designed as part of a larger ethnographic study with questions having been pilot tested among various other cultural groups and found to be feasible and acceptable. In addition to the questions in Table 1, interviewers also used exploratory follow-up questions, such as “Can you say more about that?” or “What was that like for you?” Interviews lasted between 45 and 95 minutes.

Interviewers took field notes during the interviews. The video files were professionally transcribed and verified. The video files, transcripts, and all data analysis worksheets were saved on a secure file-sharing platform approved by the Institutional Review Board. To preserve anonymity, pseudonyms have been substituted for real names in this manuscript.

Data analysis, reflexivity, and trustworthiness

The researchers were two perinatal palliative care physicians: a second-generation Taiwanese-American (BJ) and a Caucasian American (EDK). Each engaged in personal reflexivity with openness and curiosity since neither author had personally experienced a perinatal loss. The Taiwanese-American researcher helped to bring a cultural familiarity and perspective to the questions asked, at times relating questions to the societal and interpersonal awareness present in Asian-American culture. The Caucasian researcher had interviewed parents from many other cultures as part of a larger ethnographic study (Calix & Denney-Koelsch, 2024, Denney-Koelsch, 2024, Jan & Laroia, 2024), and thus brought comparative interpretation. Neither researcher engaged in direct patient care with participating families at time of perinatal loss.

This team took field notes and thematically analyzed each transcript. While videos contained identifiable information, subject numbers were assigned to recordings and transcripts to improve anonymity. All data were stored on a secure University-affiliated Box account only accessible to the team.

Transcripts were independently and manually open-coded, line-by-line, by the two researchers. Initial codes were iteratively discussed, then grouped into domains, themes and sub-themes according to the procedure described by Miles, Huberman and Saldaña (2013). The team then discussed each theme and developed a figure to visualize themes and their interrelationships. Codes that seemed to arise from a single participant were considered in constant comparison to the other codes and developing themes, leading to further refinement of the categories, themes, and sub-themes. Analysis concluded when codes began to overlap and new codes became increasingly rare indicating that thematic saturation was achieved. As the conceptual model emerged, we constantly compared to other cultural groups from our existing understanding of perinatal loss. Member checks were accomplished by having participants review the final version of Figure 1 and comment on it. An audit trail of field notes, direct quotes, and video recordings from interviews was kept to ensure trustworthiness of data.

Results

Sample

A total of six families participated in the study, including 7 parents: 5 mothers and 2 fathers. Four of the families consisted of 1 Asian American and 1 Caucasian parent. In two families, both parents were Asian American. Five of the six families participated in individual interviews and one family participated in a joint interview that included both the father and mother. Three of the families came from a support group for parents who terminated pregnancy for life-limiting fetal conditions. No parents who agreed to interviews declined participation in the study.

The Asian American parents self-identified as Cambodian (1), Chinese (2), Taiwanese (2), and Indian (1). The generational status for the Asian American parents included 5 first-generation individuals and 1 second-generation individual. In three families, parents had at least 1 other living child; in the other three families, the perinatal loss was their first child. Participants also self-identified religious affiliations as Christian (3), Buddhist (1), Hindu (1),

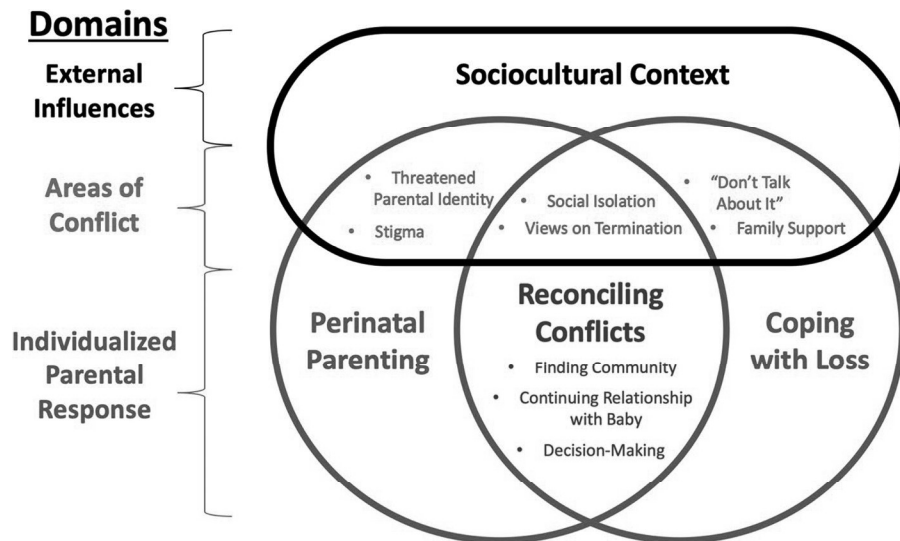


Figure 1. Asian American parental responses to perinatal loss: The interaction of domains, themes and subthemes.

Table 2. Type of losses of the study participants.

Parent (Pseudonym)		Perinatal Loss	
Mother	Father	Gestational Age	Type of Loss
Suzie	Dylan	28-week	Stillbirth
Mia		18-week	Miscarriage
Maya		22-week	Termination for Medical Reasons
Eleanor		15-week	Termination for Medical Reasons
	Hunter	20-week/14-week	Stillbirth/ Miscarriage
Melanie		30-week	Stillbirth of 1 Twin

and non-religious (2). Perinatal losses included 2 miscarriages, 2 stillbirths, and 3 terminations for life-limiting fetal conditions. Table 2 lists the type and timing of loss for the parents, using participant pseudonyms. No family interviewed had neonatal or infant deaths.

Domains, themes, and subthemes

Figure 1 shows the complex nature of the themes and subthemes within 3 domains: *External Influences*, *Individualized Parental Response*, and between these, *Areas of Conflict*. Overall, the parents' Individualized Parental Responses to perinatal loss were influenced by their external environment, in particular, the sociocultural context of their Asian American heritage, combined with their surrounding U.S. cultural influences. The domain of Areas of Conflict represented when the cultural and individual needs intersected in challenging ways.

Four overlapping themes and 9 subthemes also emerged from the data. The overarching Sociocultural Context informed, influenced, supported, or impeded families throughout the loss. The domain of Individualized Parental Responses comprised the themes Perinatal Parenting, Coping with Loss, and the ways in which they resolved cultural challenges: Reconciling Conflicts.

Themes & subthemes

The four themes and 9 subthemes are described below. Subthemes with representative quotations are shown in Table 3.

Sociocultural context

The parents' experience of perinatal loss was influenced by their sociocultural context, which refers to the milieu surrounding a parental unit, including employment, cultural traditions, generation of family immigration, degree of acculturation, cultural background of partners, religious beliefs, family dynamics, and social pressures. A multitude of external factors played an important role in contextualizing, from the perspective of others, what were and were not considered acceptable attitudes, behaviors and practices. Asian American parents had a variety of reactions to the social and cultural pressures that informed, supported, or impeded parental needs. Parents described these complexities as being caught between two cultures: the traditional Asian culture, often evidenced by family dynamics and cultural norms/expectations, and the American culture, which parents at times found more supportive or more responsive to the loss. One parent observed, "Like in America, now we are in American society, and I think things are dealt very differently here as opposed to if you would have been back home." – Melanie. Culture also informed the ways in which families coped, parented, and made decisions, as shown in the overlapping areas in Figure 1. One mother described hiding the fact that she kept the baby's remains, because it was not aligned with her Asian cultural traditions, "That's why I would

Table 3. Subthemes with representative quotations.

Subthemes	Quotes
Threatened Parental Identity	"I identify as a mom and I identify as a mom who has lost her daughter." – Eleanor "Remember that. She's not going to be replaced. I have three children, regardless of what happens during this pregnancy." – Maya
Stigma	"In terms of I'm a woman who lost a baby, there's stigma around that, right" – Eleanor "[You have] bad luck with your body...or this lady cannot have baby. Sometimes some couple they have problem because, I don't know, they just after married and did not have a baby and then they just divorce because they think cannot have baby is the reason they didn't not want to be with this lady anymore." – Suzie "And every step of the way, every step that I had to take and every medicine that I had to swallow felt like I was doing this to my baby... I would tell [my therapist] that I felt like I killed my baby. I know I didn't, but that's what it feels like." – Maya "There's a lot of self-blame, and it exasperated my experience in viewing that it was my fault somehow, and I was a bad person for not being able to grow another healthy baby." – Maya
"Don't Talk About It"	"Talking about baby loss...you just don't talk about it." – Eleanor "Asian culture, you just sweep it under the rug. You don't ever talk about bad things. You barely ever want to whisper it, God forbid." – Maya "My mom would say things, and she's not trying to be insensitive, but sometimes when I'm crying, I'm just like, "You got to stop saying that," she'll say, "Oh, don't think about it. Think about your two beautiful boys that you have. They're healthy. Be happy." I'm like, "Yeah, but it's just, you can be happy with two boys, but you can also be grieving your daughter too, which I just am." – Mia
Family Support	"How come I don't get hugs and kisses from my family?' ...And being that transition of the different generations and different cultures clashing, that's what's hard for me in my generation." – Maya "Asian parents are not very warm and fuzzy, right? And so, I didn't receive a lot of emotional support." – Eleanor "You might not want to go to the gravesite so much, because I think [my mother-in-law] thinks it's just hurting me" – Mia "My mom's not super into the herbs and things like that, but [my husband's] mom was good about giving me some teas and those jujube things and making them into tea to help my body recover" – Mia
Social Isolation	"I think a lot of people expect that you only grieve for a period of time, like a fixed period of time... But people don't understand that grief, it just stays... Time does not heal. It will hit you sometimes, and you don't know when. But it will hit you." – Hunter "But I found that people only support you through the initial moment. 'Okay, we're here. We're here.' But their lives go on. We are the ones who have to deal with this." – Hunter "My kids are in a baseball team, and there was a lady that was actually due actually two weeks before me. That was really hard because when I saw her at the game with her baby, I just hightailed it to my car." – Mia
Views on Termination	Regarding termination: "It was kind of like your stereotypical, 'You wouldn't want it anyway. This is a good thing. You're going to be able to have another. Just keep trying...'" – Eleanor "So, our baby is going to be biracial. My wife is Caucasian, and I'm Chinese. So, first regardless of what happens, she's going to look different from most people here. And then with the genetic condition, she's going to look even more different. So, [my father] said, "Okay, even if she survives, look at how difficult that's going to be for her and for us." – Hunter "And this is kind of where you see like the American first generation and like the clash with parents. It was almost kind of like, "It's a good thing that you're doing this, and you should." And she even told me, even when I first got the NIPT results, which aren't diagnostic, right... She was like, "You shouldn't even do the CVS. You should just get rid of it, right? Because why would you even want to take the chance, right?" – Eleanor "Well, my parents are in Hong Kong, so they're not here. But they were very supportive during the whole time. Actually, it was my dad trying to convince us, 'Hey, you know what? I think you guys should...induce early.' Because he was very logical...[My parents] probably don't think that our baby is a real person at the time." – Hunter
Finding Community	"The most important thing is the people <i>around</i> the people who are grieving. Because that has a big impact on them. Because grief itself is tough. For those people to go through it alone... But your surroundings, the people that you surround with can really help not really ease your pain but can really help you take a little bit of burden off." – Hunter Re sharing via email: "So that was really, really helpful in my grief, and I got a lot of people reaching out saying, 'I'm so sorry. Something like this happened to me too. I lost my daughter at 20 weeks,' and it's surprising that so many people have gone through it, and you don't know. You have no idea." – Mia "...my main reason for wanting to share was because I never wanted anyone ... to go through this experience alone." – Eleanor
Continuing Relationship with Baby	"I give them both Chinese names, too. Then there's an inscription [on the gravemarker] to describe them and the date of birth, and that's it. I just really made sure I have their Chinese name on there, so I want to make sure people know they are Chinese." – Hunter "I got this little bracelet that it screws off and you can put some ashes in it." – Dylan "My mom, older sister and younger sister, they go to pagoda and then they make food and bring to the mom and do the ceremony to just help her to rest in peace." – Suzie "We would go to these mountain overlooks and sit in our kind of foldable, collapsible camping chairs and just sit with her [urn] and hold her and talk to her and tell her what we were seeing and how beautiful it was." – Dylan "Throughout the last 11 months, I write her letters. And so I have a notebook, it has all of my letters to her, and I started to just put things in there that were any memories of any sort throughout the pregnancy. So, pictures of the positive pregnancy test, pictures from the family reveal when we told our family, pictures of the cake that we had made." – Eleanor "Somehow it came about that we were getting a fig tree. But, yeah, he planted it back there. I went on to Etsy and found this little marker that you can buy, they put their name and their dates on there. So, it's nice. It's like she's just all around." – Mia
Decision Making	"Your baby is not viable. If she survived, can you handle that? Can you handle the financial burden? Can you handle all these different things?" – father of Hunter "We also had to consider what this would mean for our daughter if we had to put all our money and time and energy to try to get everything we can for this very sick baby." – Maya "So, [the genetic counselor] was there again to talk us through deciding on an amnio or not. It was a really hard decision because... there's risk involved. It's very slim risk, but there are risks. And I didn't want any risk." – Maya "Anyway, so we did decide, we didn't have a funeral. We decided to have her cremated because we wanted to have her ashes." – Dylan

never tell my mother I have my baby's ashes at home, because I think cremation is a very strange thing for Chinese people." – Maya. She went on to explain, "That's the way culturally we just push it down. We just have to keep up appearances and kind of do what's expected."

Perinatal parenting

As the pregnancy progressed, parents described the formation of their identity as a parent to this baby, separate from their other living children. One parent remembered the bond she felt when she thought she was having a normal pregnancy, "I'm healthy and then she's healthy too. She start[ed] to move. I can feel. I still remember those feel[ings]." – Suzie. Parents stressed the significance of being viewed as a parent of the infant, even though their baby had died. Parents described how their need for parenting the child and internal feelings came into conflict with external factors such as minimization of the loss, perception of stigma, and encouragement to "move on" and have another baby. Despite having undergone loss, parents emphasized their continued desire to care for and love their child; they felt an internal sense of protectiveness, including a desire to safeguard the baby's remains. One parent said, "...the first thing I bought was just a fireproof bag. So, her ashes are still in the box sitting in a fireproof bag with her footprints, and handprints, and her death certificate. Because it's the only physical thing that I have of her." – Maya.

Coping with loss

The third theme encompasses the ways in which parents coped with the loss of their baby. At times, these behaviors conflicted with social or cultural norms. Parents specifically identified that downplaying or brushing over the loss was unhelpful. In speaking of pregnancy loss in Asian culture, one parent postulated, "it's just like it's not a big deal maybe, is what it is. And I think I really also struggled with that over the last year because I emotionally really felt like it was a big deal, and it was, it is." – Eleanor. One parent described how all memorabilia of their deceased father were removed from the home, "It's very unfortunate because I think it's another indication of what our culture does is just sweep it under the rug. When I say disappear it's because yes, we set up a funeral, a viewing, buried him. We visit him once a year at the cemetery...But I remember being back home one day—I don't remember how soon after—and every single memory of my father was essentially erased. All his belongings, shoes, and

even pictures. They were all taken away to not remember him." – Maya. Advice from the grandparents was sometimes helpful, but other times felt dismissive or minimizing. Parental coping also aligned or misaligned with their desire to remember their baby and the development of their identity as parents. Differences were also seen in the ways mothers and fathers coped. A supportive factor in coping was finding a community, such as a peer or support group, which either had experienced similar loss or was accepting of the loss that had occurred. At times, finding such a community came into conflict with the traditional Asian means of coping by not talking about the loss.

Reconciling conflicts

Faced with external influences from their culture and their families that conflicted with their individual needs, parents had to figure out a lot for themselves. At times, these areas of overlap yielded personal empowerment, with parents "doing what was right" for themselves. Maya shared "It took me a lot of work to realize what I needed and trying to acknowledge my feelings, and trying to accept my emotions, and not push them away." At other times, parents were required to reconcile external factors that were unhelpful. Hunter reconciled the external pressures and social stigma by thinking about what was best for their family, "Because I think at the end of the day, when it's life and death, you can't let other people dictate how you think, how you make a decision. They don't have to face the consequences that we do. So, at the end of the day you just have to do the best you can to take care of yourself first." Eleanor described this change in perspective, "...I wanted to tell [the baby's] truths, and I didn't care how that came down on me. Especially nowadays with how politicized and sensitive abortions are right now. And I didn't care because to me, it wasn't about me, it was about her. It was about her life, and it was about her truth. And so, I think that also contributed to just wanting to celebrate her." Parents reconciled these conflicts and external influences by finding a supportive and understanding community, continuing to honor and build a relationship with their lost infant, and making practical or values-based decisions for their family.

Subthemes (Table 3)

Threatened parental identity

The loss of the fetus or infant left parents with a threatened identity, altering their parental role from their anticipated one. They were clear that they were

parents to this baby, even if external influences made them feel dismissed or stigmatized. Dylan explicitly described, “She’ll always be our daughter and we will always love her. That doesn’t change. We’re under no delusions she didn’t die or anything like that obviously, but we’re always going to be her parents.” In the setting of the loss, parents were challenged to reconcile their dashed expectations of a healthy baby into the development of a new parental identity.

Stigma

Stigma was felt almost universally by interviewed parents: a feeling of shame, guilt or self-blame for failing to carry a liveborn infant, either through infertility, miscarriage, stillbirth, or termination for medical reasons. In particular, mothers described a sense of guilt and worried that their actions may have affected the developing fetus. One described having “bad luck” or feeling “like a bad person” because of her miscarriage. A mother who chose termination felt that she had “killed my baby” despite feeling that they made the right decision to terminate given the severity of the fetal anomalies. Parents also perceived unequal treatment from medical teams, further internalizing this as self-blame. Compared to other parents on the maternity wards, Maya described how “nobody checks on me like I’m not worthy because I don’t have a living child.”

“Don’t talk about it”

Most parents described being given advice to stay silent about their pregnancy loss or to “sweep it under the rug.” Some received explicit encouragement to not discuss the loss at all, either because talking about it was not culturally acceptable or because grandparents felt it would help their bereavement process to focus on their living children or the next theoretical baby who would be normal. They were encouraged to move on from the loss by family and friends, not just those from Asian American backgrounds. This view was propagated within the workplace, in social settings, and with extended family. The imposed silence about the perinatal loss made parents feel isolated. Many parents pushed back against this by acknowledging their own desire to speak out about their infant, “say [their] name,” and share their story. Hunter described, “...I think people don’t know what to say. And then they don’t know if we want to talk about it because they don’t know if that will make me sad... I think overall it makes them feel uncomfortable, so they want to avoid talking about that.... We actually prefer people bring up, so you actually treat them as real people instead of just a thing of the past.”

Family support

Some Asian parents felt supported by their own parents and some did not. Parents noted differences in the ways that their family expressed support from what they had expected or needed, at times lacking outward physical affection and at times failing to address their emotional needs. The encouragement from others to not talk about their babies or the loss was perceived by parents as unhelpful and did not align with what they felt was going to help their grieving. Some parents perceived encouragement to keep up “social appearances.” Other parents described how their own parents’ input was helpful and helped them to make decisions. One parent’s in-law who had experienced a loss herself was described as being supportive and able to empathize with their loss. Parents shared how different people, even among the same family, would grieve differently. “I feel like based on what I’ve seen from his family, they are definitely really open to the memorials and the tributes and doing things. I think my husband is a little bit different... I think he’s just naturally very good at compartmentalizing” – Eleanor.

Social isolation

The social discomfort, lack of cultural norms or practices, stigma and guilt, and general advice to not talk about the perinatal loss placed a burden on parents to grieve silently. Parents also described the loneliness of undergoing the loss within a maternity ward, surrounded by families who would be taking home liveborn children. Hunter described that it was painful when “we were in the same area as other couples giving birth, but they are going to go home with their babies, and we [weren’t].” Parents also shared the difficulties of seeing other healthy children. Mia described, “It’s hard. When you’ve suffered loss, it’s really hard to be happy for someone you don’t know because, in the back of your mind, not to be crass but you’re like, ‘Ugh, lucky bitch. She’s pregnant and she’s having a healthy baby,’ and you feel so much envy.” After the loss, the only people who truly knew the baby were the parents, so while others may have tried to be supportive, no one really understood their experience.

Views on termination

Multiple parents in this study felt that termination was not only permitted, but encouraged by their family when the fetus had genetic or other anomalies, and it was less stigmatized than in much of American culture. One parent’s father expressed that the baby

with anomalies was not really a person, “They are not really here.” While the intention behind such words may have been good, parents almost universally rejected this reasoning for termination, instead focusing on concerns over quality of life. Hunter described a conflict with their religious community after having undergone a termination which was supported by their Asian parents, but not their Christian church. He concluded, “If you don’t do things that your background or your religion wants you to do, you are out...You are not going to get any good, nice treatment from them at all. You are out. You are out.”

Finding community

Nearly all of the parents interviewed found solace in seeking out a community of other bereaved parents. Dylan described the importance of finding a therapist who had also undergone a perinatal loss, “because so many people don’t know what to say.” Bereavement groups allowed parents to normalize the pain of having experienced a perinatal loss. They also learned how to memorialize and received helpful suggestions for rituals. They felt they could give back to the community through participating in support groups so that others also felt less alone.

Continuing relationship with baby

All of the parents interviewed wanted a relationship with their baby, by planning and performing traditional or nontraditional rituals, and keeping their name alive by giving back to the community through physical gifts and acts of service. Many parents described a desire to honor their baby’s legacy by sharing their child’s story, celebrating milestones like birthdays, wearing jewelry with the baby’s name or ashes inside, and performing rituals like planting a tree, taking the ashes to a place with a beautiful vista, or writing letters to the baby. Many of these ideas came from other bereaved parents, rather than their own family or culture. Parents emphasized the importance of remembering their baby and including them among all of their children. Mia asserted, “I didn’t want to hide her. I didn’t want to be like, ‘Oh, we have two children.’ I have three.”

Decision making

Parents were faced with numerous decisions. The most difficult for those with a lethal fetal diagnosis was to decide whether to continue the pregnancy or terminate it. Quality of life was a significant factor in their decision-making. One family who made the painful decision to pursue termination described, “It was

very...easy in that sense in terms of ... making that decision to protect her and to ensure that she didn’t have a life of suffering, even if that meant that it’d be my life that continued with the pain and suffering” – Eleanor. Another mother who also made the decision to terminate shared, “And from our standpoint, it was always not just like can the baby survive, it’s will she have a life.” – Maya. The fact that termination was generally acceptable in their family and culture made it easier to make that decision.

Parents found themselves making other decisions based on their values as well as a sense of pragmatism. All parents had to make decisions about what to do with fetal remains, such as choosing caskets or storing ashes in urns. Hunter described the ways in which he chose a funeral home, stating “Cost. Just cost. Yeah.” In the case of the family that had lost one of two twins, parents coped by focusing on the living twin. They described, “So, we were very thankful to the god that at least we have one healthy baby and we actually focused so much on him and being more positive at that time.” – Melanie.

Discussion

This study adds to the growing body of literature on culture-specific bereavement processes, greatly expanding our understanding of Asian American parental experiences and needs surrounding a perinatal loss. The influence of social and cultural context on grief and mourning practices has previously been well described (Averill, 1968, Rosenblatt, 1988, Rosenblatt, 2008, Furtado-Eraso et al., 2021). However, to our knowledge, this study is the first to explore, depict, and define the specific interactions and conflicts regarding perinatal loss between intersecting Asian and American cultures. Perhaps because of stigmatization and encouragement of parents to stay silent about their loss, there is little in the literature about this population. Our study confirms that Areas of Conflict, existing between Individual Parental Responses to loss and External Influences, play a key role in the parental perinatal loss experience. The process of reconciling parents’ individual needs as parents with sociocultural influences may be a target for psychosocial intervention, for example by a perinatal palliative care team or bereavement caregiver. Supportive care providers can create a safe space for parents to work through conflicts between their perception of stigma and their sense of parental identity; they can work together on strategies to reduce isolation, provide opportunities to talk about their pregnancies, and normalize their need to not just “move on” from the loss.

There is a full body of evidence demonstrating that parents find it helpful to talk about their babies (Patterson, 2000, Van, 2012) and honor a memory of their loss through ritual (Kobler et al., 2007). In our study, ritual was one method by which Asian American parents found solace through their grief. In the Domain of Individualized Parent Response, parents coped with the loss and felt like good parents by maintaining emotional bonds with their babies. They found ways of continued meaning making, often adapting nontraditional rituals such as candle lighting, tree planting, and bringing mementos such as their baby's ashes to beautiful locations. Many of these ideas came from their community supporters and not from their cultural heritage. Unlike rituals performed in traditional cultures—for example, when mothers in Taiwan who had experienced a stillbirth felt compelled to perform rituals to placate the ghosts of their unborn children (Hsu et al., 2002)—parents in this study found comfort in creating new rituals for themselves to honor their child. These formed continuing bonds that helped to combat social stigma and isolation (Neimeyer et al., 2006). We suspect that these findings apply to other immigrant populations, who also struggle to reconcile their traditional beliefs, norms, and expectations to the prevailing culture within the U.S. We have reported similar experiences and stories with bereaved Muslim-American parents, who described that some relatives in their country of origin recommended not talking about their babies (Denney-Koelsch, 2024). Likewise, Latino-American immigrant parents are reported to struggle with the stigma of not being able to carry a baby to term (Calix & Denney-Koelsch, 2024).

A key to reconciling cultural conflicts for Asian American parents in our study was the important parental task of decision making. In making decisions, parents focused on what they needed as individuals and as a couple. Given their Asian families' recommendations not to talk about their baby, some parents in our study chose to join support groups, deciding to speak about their experience with parents who had lived through similar losses and share their own stories. Parents in support groups were much more able than family members to understand and sympathize with the bereaved parents and encourage strategies to cope with loss through some of the memory making ideas described above.

Another key decision for some parents was whether to terminate a pregnancy with a life-limiting fetal condition, a decision ultimately made by three families in this study. The sociocultural context affected the parents' concept of when a fetus or infant becomes a

person and how a termination was viewed. They considered the perspectives of their family, their Asian culture, as well as of their American peers and church communities. Often, extended family members not only understood, but encouraged parents to pursue termination for the infant's and family's sake. Most parents in this sample accepted termination as a reasonable decision for severe fetal anomalies, focusing first and foremost about the child's future quality of life. They pragmatically considered practical or financial realities if they maintained the life of a severely impaired child. These parents expressed love for their baby and grief as they made decisions for what they felt was best. Given the *Dobbs v. Jackson Supreme Court* ruling in 2022 (Dobbs v. Jackson Women's Health Org, 2022), many parents across the U.S. are limited in their access to termination within their own states. Parents whose cultural backgrounds encourage termination, but now lack the choice of whether to carry a baby with a lethal condition to term, are likely have different pregnancy and bereavement experiences from the three parents in our sample who chose to terminate.

Nearly all parents in the present study experienced social isolation, either explicitly from reactions in their religious communities or workplaces, or implicitly from perceived cultural blame and stigma. Parents in this sample strongly advocated for finding peers or professionals who have experienced similar bereavement, a view strongly expressed in our previous studies and those of others (Côté-Arsenault & Freije, 2004, Côté-Arsenault & Denney-Koelsch, 2011, Simpson et al. 2015, Denney-Koelsch, 2024). Healthcare professionals should therefore be equipped with resources and be open to discussing parental experiences in a cultural context. An interdisciplinary team involving social workers, chaplains, bereavement and palliative care specialists can work with families to address their goals, values, and cultural needs throughout their pregnancy and bereavement. In addition to asking about specific cultural rituals or traditions which families would like to follow, palliative teams can elicit specific personal goals of the parents. This can be clarified through questions on how parents are coping, such as:

What has been helpful or unhelpful in your family?

How is your family responding to your loss?

What would be most helpful for you at this time?

Then one could make some normalizing suggestions, such as:

Some parents have found it helpful to meet others going through a similar experience. Would that be helpful for you?

A final important consideration while providers interact with these parents is the need for cultural humility, avoiding assumptions or prejudiced thinking about another person's culture. Cacciatore (2009), in an exploration of Native American families experiencing a perinatal loss, describes the importance of "working toward an aware, but not presumptive, respect-based treatment intervention." Cultural competence requires a desire to learn from others' cultures, while balancing the individual and personal needs of specific families. In future research, we seek to develop culturally sensitive interventions and tools for all clinicians who interface with parents of all cultures surrounding perinatal loss or palliative care.

Limitations

Although the sample size for this study was small, the parents' words are rich with meaning and context. There was unintended sample bias, because three of the seven participants came from a single support group for those who terminated pregnancy for life-limiting conditions. We originally intended to recruit parents who had continued their pregnancies and had infants who lived for a period of time after birth, but all of the losses in our sample occurred prior to 28 weeks' gestation and none were born alive. Half of our sample were either Chinese or Taiwanese, which share significant cultural overlap. Over half the couples in the sample consisted of one Caucasian parent and one Asian parent; their perspectives may be less reflective of Asian Americans, but do represent mixed culture couples. Further research should include a larger sample size, with a greater diversity of different Asian American minority groups representing various countries of origin. A larger sample should also be inclusive of a broader diagnostic pool, including losses of liveborn children, for a more holistic understanding of cultural influences on the Asian American experience of perinatal loss.

Conclusion

The cultural aspects of perinatal loss have been of increasing academic interest in recent years, but Asian American populations have often been overlooked and underrepresented in this literature, possibly because of cultural stigmatization and encouragement of silence. This study demonstrates a common taboo within certain traditional Asian cultures against speaking about infant loss, and also cultural differences in acceptance of fetal termination in the case of life limiting conditions. This preliminary study elucidates social and

cultural challenges faced by Asian American parents dealing with perinatal loss.

Our findings highlight the need for cultural humility and openness by providers in discussing with parents their personal needs and preferences regarding decision making. Providers need to be sensitive to the complex familial Sociocultural Context, help to foster Perinatal Parenting and Individual Coping, and facilitate parents' Reconciliation of Cultural Conflicts. Interdisciplinary perinatal supportive care teams should normalize talking about the baby, facilitate individualized rituals and memory-making, and offer referrals to support groups. They can also work with families to help reconcile cultural family conflicts, if this assistance is desired. Ultimately, our goal is to improve long-term bereavement outcomes for all parents after they have experienced heart-wrenching perinatal loss.

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